

Paediatric Palliative Care

(<https://palliativecare.org.au/children>)

Menu



'Nurse' by Georgia

Diagnosis/Recognition

There are different ways a family might receive a diagnosis or recognition of a life-limiting illness. There are three common ways a diagnosis or recognition process starts;

1. A parental concern
2. A health professional concern
3. A critical event

While some children may be given a diagnosis of a known disease or condition, not all children will receive a diagnosis. Sometimes the cause of the condition may never be known and this can make it harder for families to access support and information on how best to live with and manage the symptoms.

Every family should be informed of their child's prognosis in a sensitive, respectful and honest manner. Sharing this news is a difficult task for most health professionals but it is important to remember that this experience often stays with parents for a long time. When sharing the prognosis, try and ensure there is sufficient time and privacy to have a face-to-face conversation with the family. The information should be provided in a way that the family can understand and written information can be used to support the conversation. For health professionals who are uncertain on how to share the prognosis with the family, ask for assistance from a senior staff member.

This time can be devastating for families and people may experience many different emotions, including shock, fear, helplessness and denial. How people respond to the news of a diagnosis or recognition of an illness or condition will be unique to them and you need to be able to support them through this time.

Try and identify some emotional and practical support options for the family, for example a condition specific support groups or a social worker. Some suggestions are available from [information, support services and resources](https://palliativecare.org.au/download/10865/). (<https://palliativecare.org.au/download/10865/>)

Resources developed specifically for family members are also available from the *For Carers* (<https://palliativecare.org.au/carer-resources/diagnosis>).

A Family Companion (<https://palliativecare.org.au/download/10882/>) is a 38 page resource designed to summarise many of the situations and challenges that people may experience as a parent and carer of a child with a life-limiting condition or illness. The complementary family orientated factsheets are available from the [all resources](https://palliativecare.org.au/children/all-resources) (<https://palliativecare.org.au/children/all-resources>) page. The resources are now available in four additional languages: Arabic, Simplified Chinese, Traditional Chinese and Vietnamese.

For additional information on guidelines for the provision of paediatric palliative care in Australia, please refer to the below resources:

- Children's Health Queensland Hospital and Health Service's *A practical guide to palliative care in paediatrics* (2014)
- *Palliative Care Australia's Standards for Providing Quality Palliative Care for all Australians* (2005). (<https://palliativecare.org.au/policy-and-publications/the-national-standards/>)
- Australian Commission on Safety and Quality in Health Care's *National consensus statement: essential elements for safe and high-quality paediatric end-of-life care* (2016). (<https://www.safetyandquality.gov.au/publications/national-consensus-statement-essential-elements-for-safe-and-high-quality-paediatric-end-of-life-care/>)

Acknowledgement: Together for Short Lives 2013, A Core Care Pathways for Children with Life-limiting and Life-threatening Conditions, 3rd edn, Together for Short Lives, Bristol.

Useful resources for Diagnosis/Recognition

Transferring a Child Requiring Palliative Care Home

This prompt sheet outlines a process for health professionals to transfer a child receiving palliative care to their home. This is to ensure appropriate planning is undertaken to prepare, empower and support the child, family [...]

VIEW → ([HTTPS://PALLIATIVECARE.ORG.AU/TRANSFERRING-A-CHILD-REQUIRING-PALLIATIVE-CARE-HOME](https://palliativecare.org.au/transferring-a-child-requiring-palliative-care-home))

Advance Care Planning

Advance care planning is a process to discuss the child's and their family's values, goals and hopes and identify their future healthcare preferences. Advance care planning often takes place through a number of conversations and [...]

VIEW → ([HTTPS://PALLIATIVECARE.ORG.AU/ADVANCE-CARE-PLANNING](https://palliativecare.org.au/advance-care-planning))
